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Qualitative interviews with non-national tuberculosis patients in Cairo, Egypt: understanding the financial and social cost of treatment adherence

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Abstract

Limited data are available about the challenges of non-national TB patients undergoing long-term treatment courses in an urban setting. This study aimed to understand the financial and social cost of adherence of non-national TB patients in Cairo, Egypt as a means to inform the development of context-specific interventions to support treatment adherence. In 2011, 22 in-depth interviews were conducted with TB patients from Sudan, Ethiopia, Eritrea, Somalia and Djibouti to obtain qualitative data. Analysis was based on thematic analysis that aimed to identify recurrent themes and codes from the narratives. The study identified a number of factors that influence TB treatment adherence. Uncertain financial status due to limited or no employment was frequently discussed in interviews, which resulted in fear of not being able to support family, loss of pride, dependence on family and friends, fear of losing housing, food insecurity and limited food options. Respondents also feared infecting other household members and longed for opportunities to discuss their illness and treatment experiences with other individuals but their social networks

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were often limited. TB-related stigma was driven by shame and blame of infection. Respondents also believed stigma was based on their foreign origin. Stigma manifested in distancing and exclusion in various ways, resulting in isolation, psychological distress and reluctance to disclose TB status to others. Poverty-related factors and social context with a special focus on stigma should be considered when developing strategies for supporting long-term treatment courses for non-national patients in Cairo and other similar urban settings.

Keywords

refugee and asylum seeker healthcare; respiratory medicine; social determinants of health

Introduction

Tuberculosis (TB) remains a major public health problem in Egypt with an estimated 17 cases per 100,000 in the general population in 2013 (World Health Organization 2014a,b). It is an increasingly important cause of morbidity and mortality among displaced populations in the world (WHO 2007, Hadzibegovic *et al.* 2009). The numbers of non-national mobile populations in Egypt including refugees, asylum seekers and migrants have rapidly grown between 2011 and 2013 as a consequence of the Syrian armed conflict. In April 2015, the United Nations High Commissioner for Refugees (UNHCR) estimated that Egypt hosts over 184,000 refugees and asylum seekers representing some 67 different nationalities. There is a growing need to include non-national populations in health planning including developing TB care and treatment strategies for them.

Non-national mobile populations are vulnerable to TB in their countries of origin because their health status depends on the availability of and access to quality health systems, overall socioeconomic conditions as well as the occurrence of national emergencies such as famines and political conflicts. During migration, mobile populations are at risk for TB, particularly if travel occurs under precarious conditions including limited access to healthcare, incidents of violence or being kept in detention centres with poor nutrition and ventilation. Individuals who have experienced abuse by officials, traffickers or by host community members during migration may also be reluctant to seek medical assistance. In the host country, the risks of contracting and effectively treating TB are linked to the integration of non-national populations into the host country's health system, their living and working conditions and socioeconomic status (Rysstad & Gallefoss 2003, WHO 2005, Kimbrough *et al.* 2012, World Health Organization and International Organization for Migration [WHO/IOM] 2014).

Patient non-adherence to treatment regimens remains a major obstacle in TB control programmes worldwide. Interrupted treatment may result in relapse, the emergence of drug resistance including multidrug-resistant tuberculosis (MDR-TB), ongoing transmission of TB and even death (Volmink & Garner 2006). Although healthcare and treatment regimen-related factors shape treatment adherence, individual and social factors, the economic burden of the illness and TB risk perceptions influence treatment observance (Greene 2004, Watkins & Plant 2004, Munro *et al.* 2007, Tomas *et al.* 2013). Previous studies in Pakistan, Ethiopia,

India, Nepal and China have linked financial and employment situations to treatment adherence (Khan *et al.* 2000, 2005, Demissie *et al.* 2003, Jaiswal *et al.* 2003, Wares *et al.* 2003, Wyss & Alderman 2007, Wei *et al.* 2009). In Nepal, treatment adherence has also been linked to family and community influences (Wares *et al.* 2003, Watkins & Plant 2004) and in India, South Africa, Vietnam, Pakistan and Ethiopia to stigma (Nair *et al.* 1997, Edington *et al.* 2002, Johansson & Winkvist 2002, Demissie *et al.* 2003, Khan *et al.* 2005).

Currently in Egypt, the right to TB treatment regimens for all non-Egyptian populations is ensured, regardless of their legal status. Treatment is provided free-of-charge by the National TB Programme (NTP) and non-governmental organizations (NGOs) with the support of UNHCR. NGO-based TB clinics provide first-line drug treatment and implement a WHO-modified directly observed therapy (DOT). These clinics request patients visit the clinic every 2 weeks to meet with a dedicated physician and to receive medication. At the NGO clinics, patients also receive a food aid bag including milk, beans, peanut butter, oil, sugar, cheese and honey. The NTP provides laboratory services and inpatient care for the most seriously ill patients as well as second- and third-line drugs. Through its NGO partners, UNHCR offers refugee and asylum seekers with monthly financial assistance ranging between US\$ 57–170, depending on the family size and other contextual factors, throughout their treatment duration.

Because no previous studies describe the financial or social challenges of non-national TB patients in Cairo during their TB treatment course, this study intends to bridge this gap. It is particularly relevant as it reflects the World Health Assembly (WHA) Global TB strategy (2014) that focuses on learning about the epidemic and reaching the most vulnerable populations. The WHA strategy highlights the need to build cultural competency regarding the needs of mobile populations and to ensure that TB diagnostics, care and treatment are adapted to the needs of these populations (WHO/IOM 2014). The findings of this study can be used by service providers and policy makers to develop new tools and approaches to better support non-national TB patients in an urban setting during treatment.

Methods

Design

The study was conducted between September–December 2011 among refugees, asylum seekers and migrants in two NGO-operated TB clinics and a government chest hospital in Cairo that are known treatment centres for non-national TB patients in the country. A structured questionnaire was developed to obtain demographic information including housing situations and changes in sources of income during the treatment. An open-ended, in-depth interview guide with a set of probes was developed to elicit narratives about the experiences during the treatment. The question guide included questions such as: ‘Tell me about the time you were treated for TB? What did you consider difficult during the treatment? Tell me about the people you were in contact with during your treatment? Describe your housing situation during treatment’. The questionnaire and the guide were translated and back-translated from English to Arabic by a professional translator.

Recruitment and sampling

Those eligible to join the study included all non-national adult patients (≥ 18 years) who had been recorded in the TB clinic logbooks as having received TB treatment for pulmonary or extra-pulmonary TB between January 2010 and March 2011, and who had completed the treatment or defaulted ($n = 73$). Study co-ordinators contacted eligible adults by phone. Three attempts were made to reach all eligible patients by phone at different times of day which resulted in a sample of 22 study participants.

Procedures

A group of 15 NGO staff members experienced in research activities and working with non-national populations were invited to participate in a 4-day training workshop conducted by the investigators of this study to learn about qualitative data collection methods and research ethics. Five NGO staff members were selected following a pilot that assessed participants' skills in qualitative interviewing. All patient interviews were conducted on NGO or Ministry of Health premises, except two which were conducted in respondents' homes because they were wheelchair-users. All interviews were conducted in a closed room. Each interview started with verbal consent that was audio-recorded. At the end of each interview, the interviewer revised the main issues discussed to ensure that they adequately reflected the participants' lived experiences. Each interviewer conducted one to two interviews per day, each lasting from 30–90 minutes. Interviews with non-Arabic and non-English speakers from Somalia and Eritrea were conducted with a professional translator reading from the English questionnaire. Interviewees were compensated the cost of their transportation (US \$ 5). Data were collected over a period of 1 month.

Analysis

Data analysis began immediately after each interview during a debriefing session between the investigator and interviewers. In the debriefing session, interviewers reviewed the main findings, shared their experiences and observations with the investigator, and identified issues to be investigated. The sessions also informed the investigator about data saturation. Interviewers wrote short field notes during the interviews and elaborated on them immediately after the debriefing session. Field notes and debriefing notes were translated from Arabic to English by a professional translator.

Interviews were audio-recorded, transcribed and translated from Sudanese Arabic, Tigrinya, Amharic, Somali and Egyptian Arabic into English by professional translators. Quality control of the transcriptions was conducted for approximately 50% of transcriptions and translations of Amharic, Tigrinya and Amharic to English by professional translators. A bilingual investigator conducted random quality checks on 30% of the Arabic transcriptions and translations to English. When discrepancies between the audio tapes, transcriptions and translations were identified, the interviewer, the translator and the investigators met to identify ways to correct them.

Thematic analysis was utilised to analyse the data (Brown & Clarke 2006). The analytical process started with investigators familiarising themselves with the data, which included reading printouts of the translated transcriptions several times followed by open coding that

included highlighting words, phrases and sentences related to challenges during the treatment course in order to extract the initial set of codes. The highlighted sections were jointly reviewed by the authors of the study who established the final set of codes by consensus. The analysis continued by cutting the highlighted sentences from the transcripts and developing a chart onto which the relevant codes were sorted. The codes were merged into larger categories and finally grouped under two main themes: financial status caused by unemployment and social context. The themes were split into nine sub-themes and jointly revised again by the same group of study authors to ensure they sufficiently answered the research questions. Once a sub-theme 'stigma' was identified, the conceptual framework of Stangl *et al.* (2012) was used to break down the stigma into components that are measureable and can be addressed through programme and policy recommendations, which included drivers, manifestations and outcomes of stigma. Self-stigma, anticipated and experienced stigma were analysed separately (Stangl *et al.* 2012).

Extended field notes were used during the analysis process for triangulation purposes. In the final stage of the analysis, the first author of this study identified the key characteristics and made the final interpretation of the data set as whole.

Ethical considerations

The study was approved by the Institutional Review Boards of the U.S. Naval Medical Research Unit no 3 and the Centers of Disease Control & Prevention (CDC) as research that does not require ethical review. All interviews began with verbal consent. No forms of personal identification were collected and all interviews were conducted in a private room.

Results

Description of participants

A total of 59 NGO and 14 government hospital patients were eligible to join the study; 20 NGO and two government hospital respondents agreed to participate, nine refused participation and 42 could not be reached after three attempts. One interview was refused by investigators because the patient sent a neighbour to the interview. Participants included 10 males and 12 females with a mean age of 30 years (range: 18–55 years). Eleven participants had refugee status and the remaining were asylum seekers and migrants originating from Sudan, Somalia, Eritrea, Ethiopia and Djibouti.

The majority of participants (17/22 patients) had completed primary and preparatory school, three participants had no formal schooling and two held university-level degrees. Ten participants were married and 12 were single, separated or divorced. Sixteen respondents were unemployed during their treatment, one respondent had a full-time job and five were students. Thirteen respondents had pulmonary TB and nine had extrapulmonary TB, all had received first-line drugs. Three respondents had a period of treatment default (one single, male Sudanese migrant; one married female Somali refugee; and one divorced, female Sudanese migrant). At the time of interview, all respondents, including those who had previously defaulted, had completed their treatment.

Participants lived with an average of five persons per household in an average of 2.1 rooms/household. The majority of participants lived with family members or relatives during their TB treatment and several lived with friends. One male reported living alone and one female reported having no permanent place to live.

Over half of respondents relied on only one source of income, usually family members living in Egypt. One respondent depended entirely on the UNHCR monthly allowance. One female Sudanese patient travelled to Egypt specifically to receive TB treatment; her relatives abroad covered her expenses. The rest either had two or three sources of financial support that included UNHCR monthly allowances, financial assistance from family or friends, or donations from a charity organisation.

Theme 1: Poverty—Poverty caused by unemployment was a widely discussed theme that generated six sub-themes including loss of pride, pressure of not being able to support family, stress of being dependant on others, fear of losing housing, lack of food and limited food options (Table 1).

Nine respondents, including six females, were fully employed before learning about their TB status, but only one was able to keep her job during TB treatment. One respondent was asked to stop working by his doctors to concentrate on treatment. Two respondents lost their jobs after their employers learnt about their TB status:

They [employer] told me to leave. They were afraid of me. (Eritrean female patient)

Two female respondents stopped working due to their fear of infecting others. The rest stopped working because they felt too sick to work:

I wasn't working. I couldn't even walk; how I could have worked? (Sudanese male patient)

Concern about not being able to provide financial support for their family was frequent. Female respondents, in particular, raised concerns about losing their income:

Men don't get jobs, they rely on us. I was desperate when I could not work. I did not know how to feed my family. (Sudanese female patient)

However, a few male respondents also reported that their loss of income led to a loss of pride given their traditional male role as the breadwinner of the family. These male respondents reported intra-familial conflicts. They also experienced blame for their inability to provide for their family:

My family did not speak to me. My wife looks tired and she thinks I am good for nothing. (Somali male patient)

Dependence on family and friends caused insecurity and stress for many respondents. Financial support was often provided in the form of a daily or weekly allowance or on ad hoc basis:

Some days they gave me some money. Other days they [friends] told me that I have to manage on my own because they had nothing to give me. (Djiboutian male patient)

Fear of losing housing was prominent, yet only two respondents were unable to pay rent and had to move. Those who lived with family or friends without contributing to housing expenses were afraid of being asked to leave because of the hosts' lack of resources:

I am here now, but I don't know for how long. Maybe they don't want me to stay because I am so sick. (Sudanese male patient)

Only a few respondents claimed they had insufficient food during treatment, including a female who relied on food offered by acquaintances and another who often took her medication on an empty stomach:

I used to wait to see if they [friends] would serve me breakfast or not. Most days they did not. Sometimes I felt so weak with my empty stomach. (Sudanese female patient)

Many respondents reported eating mainly beans, lentils, rice and macaroni because of their inability to purchase other items. They longed to eat vegetables and fruits, drink milk and add variety to their daily diet:

I used to have bread or Somali pie in the morning. At noon, we used to have lunch and eat whatever is available, rice or macaroni. At night we ate bread. (Somali female patient)

I wanted to drink milk but it was never available. (Somali male patient)

Theme 2: Social context—The sub-themes that emerged from this theme included fear of infecting other household members, lack of social contacts and stigma.

Several participants, excluding those with extra-pulmonary TB, had difficulty finding private space at home and lived in fear of infecting others. Respondents were fearful of being in the same room or sleeping in the same rooms with their family members. Several female respondents feared infecting their children while caring for them:

When I came home, I went to my room, closed the door and sat there alone. I did not speak to them. I did not want to infect them. (Sudanese male patient)

One female Somali respondent was especially saddened by her situation and not being able to have close contact with her children:

I did not know what to do with my children. They don't know why I keep my distance. At night I pray to God that I won't infect them. (Somali female patient)

Many respondents cited having only a few people with whom to discuss TB issues and most of them longed having someone to talk to about it. Several respondents also believed that having people remind them to take their medication facilitated adherence, but many did not have such support:

I did not talk to many people and there were not many who came and asked me about my disease. (Sudanese male patient)

I would have wanted to talk to somebody, to anyone, especially when they prolonged my medication. I was so desperate. I did not believe this [TB] was going to end. (Eritrean female patient)

Some female Somali respondents were not in regular contact with the surrounding community and spent most of their time at home with their husband and young children. One explained not having discussed her illness with anyone. Another visited the hospital with her husband to receive her medication but communication with the doctor was left to her husband:

I don't know what I had. I did not ask. I had no one to ask. This is my life. (Somali female patient)

No, I don't have anyone to talk to. We don't go out or talk to anyone. (Somali female patient)

Fear of stigma was prevalent among most respondents. In general, Somali respondents were less concerned about stigma than respondents originating from other countries. Many Somali respondents explained that TB was a common illness. On the contrary, Sudanese respondents were more concerned about the stigma than other respondents. Narratives of stigma included self-stigma, fear of being stigmatised and actual experiences of stigma.

TB stigma was linked to the concept of shame as TB was perceived as 'a bad disease' or 'big shame':

I was so embarrassed for having this shameful disease. I used to go out only after dark. I was so shy to meet anyone. (Sudanese female patient)

TB was linked to the concept of death, which increased fear about it:

People look at you and they think of death. They don't know this [TB] is treatable. (Ethiopian female respondent)

Several respondents mentioned that they were blamed for the infection:

When you have TB, they think you did something wrong. They think you are not clean or that you don't live in a clean place. (Djibouti male respondent)

Your neighbours may think that you are not good. You did something that you got this illness. (Eritrean female responded)

Respondents believed that one of the underlying drivers of TB stigma was stigma towards people of foreign origin:

As a foreigner, people may question your morals, they may question your hygiene. So they think you may have something. (Somali female patient)

People think I am uneducated and I don't understand anything just because I'm from Sudan. They think that is how I got this illness [TB]. (Sudanese male patient)

Self-stigma manifested in isolation and distancing from other people:

When people learnt I had TB, I stayed in my place. I used to sit to the side to avoid them. (Sudanese male patient)

I never ate when I visited friends, even if I was hungry, because I was afraid they would all stop eating and leave the table. (Sudanese female)

Many other respondents also experienced stigma. The manifestations of stigma included distancing behaviour, unwillingness to share dishes or sit with TB patients in close proximity, refusal to conduct customary social visits and abandonment. Several respondents said stigma from their own household was the worst form. One female respondent experienced harsh verbal abuse and gossiping from her neighbours:

If I had paid attention to all things people said about me, I would have died from sadness. (Sudanese female patient)

Nobody came to visit me in the hospital. When they came to my house they stayed far away from me. I felt so bad. (Sudanese male patient)

Stigma resulted in isolation, psychological distress and unwillingness to disclose TB status. All respondents had disclosed their status to someone in their household, but only a few shared their status outside their homes.

I moved to a new area. I did not tell anyone about my condition. I called by mother in Somalia. She is the only one who knew. (Somali male patient)

I felt that I could never share my TB status with anyone. I have to manage this all by myself. (Djibouti male patient)

I was afraid of people. I was afraid they may hurt me or send me away. (Ethiopian female patient)

Discussion

This study reveals a number of poverty-related and social factors that non-national TB patients face during the treatment course. As a result of regional conflicts over the last 15 years, Egypt has experienced a rapid increase in non-national populations, especially in the megatropolis of Cairo. Understanding the needs of urban non-national populations is paramount to justifying and planning the reallocation of resources to strengthen health systems used by these populations. This study provides valuable information about the challenges of non-national TB patients in Egypt during their long treatment period, identifies several opportunities for improving support during the treatment period, and supports numerous practical, strategic recommendations for both service providers and national policy makers.

Our findings show that respondents were concerned about their financial situation and unemployment, because of their financial dependence on others, concerns about not being able to support their family, loss of pride, fear of losing housing, lack of food and a limited variety of fresh vegetables and fruits. Many studies point out that financial factors and unemployment can negatively influence treatment adherence (Khan *et al.* 2000, 2005, Demissie *et al.* 2003, Jaiswal *et al.* 2003, Wares *et al.* 2003, Wyss & Alderman 2007, Wei *et al.* 2009). Cairo, similar to other large cities that attract non-national mobile populations, is often viewed as an opportunity for greater self-reliance compared to refugee camp alternatives. However, because Cairo has high unemployment rates, non-national

populations have limited employment opportunities, mainly as low paid, informal domestic labourers (Al-Sharmani 2003, Brown *et al.* 2004). In our study, most TB patients did not benefit from job opportunities and those who had, either lost or gave up their job during TB treatment because of the fear of infection and taxing physical demands. Numerous studies among TB patients, including refugees and immigrants in various countries, also highlight similar employment-related problems (Johansson *et al.* 1999, Khan *et al.* 2000, 2005, Edington *et al.* 2002, Jaiswal *et al.* 2003, Greene 2004, Kirwan *et al.* 2009, Thomas *et al.* 2011). Female respondents expressed stronger fears of job loss than men. Women in non-national families tend to be the primary breadwinners of the family, especially among Sudanese, Eritrean and Ethiopian families, because they are preferred as domestic labourers (Jureidini 2009). Low-cost governmental housing in large cities such as Cairo is limited and reserved for nationals, leaving non-national populations to rent from the open market where prices often exceed their income. Some manage to cover rent partly with the UNHCR allowance but are still left to manage all other living expenses. Many respondents lived with friends or family members, as reported in other studies among Sudanese and Somalis in Cairo, as means of coping with limited financial resources (Al-Sharmani 2003, Grabska 2005).

These challenges highlight the need to create channels to meet the basic needs of TB patients including employment, housing and nutrition during their illness and treatment. In Peru, innovative economic interventions including food and cash transfers and microcredit increased treatment completion (Rocha *et al.* 2011). Policy makers may need to consider developing a food security and nutrition strategy for TB patients that would ensure the availability and quality of food during treatment.

TB patients in our study did not have large social networks, worsening their fragile financial situation compared to nationals or refugees in a camp setting who are likely to have larger social networks during treatment (Bohler *et al.* 2005). Small social networks also gave non-national populations little opportunity to discuss TB, which was considered highly important among study participants. Previous studies among refugees have identified social networks as a valuable coping mechanism (Muhwezi & Sam 2004, Willems 2005, Thomas *et al.* 2011) and studies among TB patients in various settings have identified social support as an important factor influencing treatment adherence (Ito 1999, Wares *et al.* 2003, Watkins & Plant 2004). Cultural factors shaped the social realities of some female respondents by limiting their social interaction to their husband and children, thereby reducing their opportunities for social support relative to male patients. Special attention should be given to gender-based needs of TB patients, an area that has been often neglected by TB programmes worldwide (Diwan & Thorson 1999, Chan *et al.* 2013).

Support groups for TB patients have been successful in other countries (Acha *et al.* 2007, Rocha *et al.* 2011). House calls by health providers who provide social support in the U.S. showed improved treatment adherence (Irabarren *et al.* 2013). Programme planners should consider developing culturally appropriate ways to support social networking among non-national TB patients that would allow them to share their experiences in their own language

Our results indicate that TB-related self-stigma, fear of being stigmatised and experiences of stigma impacted the lives of respondents leading to isolation, psychological distress and unwillingness to disclose their TB status. This is similar to studies in Spain, in the U.S. and in Canada, where stigma was shown to impact refugee and immigrant TB prevention and treatment (Yamada *et al.* 1999, Atre *et al.* 2004, Coreil *et al.* 2004). The root causes of stigma in our study were linked to shame, blame for infection and the concept of death. The respondents were also burdened by stigma due to their foreign origin, which was likely to increase their stigma burden compared to national TB patients. Similar experiences of such intersecting stigmas have been documented among foreign populations in other countries (Yamada *et al.* 1999, Coreil *et al.* 2004).

These root causes of stigma need to be addressed when developing stigma-reduction strategies, as interventions based on drivers of stigma have been shown to improve stigmatising attitudes among patients and the community (Stangl *et al.* 2012). As TB stigma was driven by the concepts of shame and death, an anti-stigma campaign can include messages that alter them such as advocacy that anyone can get the disease and that TB is a treatable infection. Recent TB stigma-reduction interventions have successfully used the empowerment of individuals to resist stigmatising attitudes while working on changing community norms about the disease (Gibson *et al.* 2005, Daftary & Padayatchi 2012). Similar strategies should be considered for non-national populations in an urban setting. Outreach activities, including stigma-reduction interventions, should also address patient confidentiality, the provision of consultations for family members and friends of patients to alleviate TB fears, and training of healthcare providers to ensure provision of stigma-free TB services.

Our study has potential limitations. As the study was conducted after the completion of treatment, over half of study participants could not be reached, possibly resulting in selection bias. Participants' experiences may have been subjected to bias due to social desirability as the interviews were conducted in the TB treatment clinics where the respondents had received their treatment. Despite these limitations, our findings are consistent with existing international literature discussing TB treatment experiences.

Conclusions

Non-national TB patients in an urban setting require special considerations due to poverty-related factors and social environment, which are likely to create challenges to treatment adherence. Support strategies need to reflect basic needs such as income, housing and nutrition. However, they also need to consider social support and gender-based factors and stigma-reduction interventions. Adopting an enhanced national strategy including a contextualised perspective of non-national populations is critical to the development of patient-sensitive and socially responsive interventions that support treatment adherence.

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References

- Acha J, Sweetland A, Guerra D, Chalco K, Castillo H, Palacios E. Psychosocial support groups for patients with multidrug-resistant tuberculosis: five years of experience. *Global Public Health*. 2007; 2(4):404–417. [PubMed: 19283636]
- Al-Sharmani, M. Working Paper 2. American University in Cairo; 2003. Livelihood and Identity Constructions of Somali Refugees in Cairo. Available at: <http://www.aucegypt.edu/ResearchchatAUC/rc/cmrs/reports> [accessed on 4/11/2014]
- Atre SR, Kudale SM, Morankar SN, Rangan SG, Weis MG. Cultural concepts of tuberculosis and gender among general population without tuberculosis in rural Maharashtra India. *Tropical Medicine and International Health*. 2004; 9(11):1228–1238. [PubMed: 15548321]
- Bohler M, Mustafaa SA, Morkve O. Tuberculosis treatment outcome and health services: a comparison of displaced and settled population groups in Khartoum, Sudan. *International Journal of Tuberculosis and Lung Disease*. 2005; 9(1):32–36. [PubMed: 15675547]
- Brown V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006; 3(2):77–101.
- Brown NR, Riordan SS, Sharpe MM. Developments: the insecurity of Eritreans and Ethiopians in Cairo. *International Journal of Refugee Law*. 2004; 16:661–701.
- Chan AH, Polesky A, Bhatia G. House calls by community health workers and public health nurses to improve adherence to isoniazid monotherapy for latent tuberculosis infection: a retrospective study. *BMC Public Health*. 2013; 13:894. [PubMed: 24073620]
- Coreil J, Lauzardo M, Heurtelou M. Cultural feasibility assessment of tuberculosis prevention among persons of Haitian origin in South Florida. *Journal of Immigrant Health*. 2004; 6(2):63–69. [PubMed: 15014223]
- Daftary A, Padayatchi N. Social constraints to TB/ HIV health care accounts from coinfecting patients in South Africa. *AIDS Care*. 2012; 24(12):1480–1486. [PubMed: 22530855]
- Demissie M, Getahun H, Lindtjorn B. Community tuberculosis care through “TB clubs” in rural north Ethiopia. *Social Science and Medicine*. 2003; 56(10):2009–2018. [PubMed: 12697193]
- Diwan VK, Thorson A. Sex, gender and tuberculosis. *Lancet*. 1999; 353(9157):1000–1001. [PubMed: 10459926]
- Edington ME, Sekatane CS, Goldstein SJ. Patients’ beliefs: do they affect tuberculosis control? A study in a rural district of South Africa. *International Journal of Tuberculosis and Lung Disease*. 2002; 6(12):1075–1082. [PubMed: 12546115]
- Gibson N, Cave A, Doering D, Ortiz L, Harms P. Socio-cultural factors influencing prevention and treatment of tuberculosis in immigrant and Aboriginal communities in Canada. *Social Science and Medicine*. 2005; 61(5):931–942. [PubMed: 15896894]
- Grabska, K. Living on the margins: the analysis of the livelihood strategies of Sudanese refugees with closed files in Egypt. The American University in Cairo, Center for Migration and Refugee Studies; 2005. Available at: http://www.aucegypt.edu/ResearchchatAUC/rc/cmrs/reports/Documents/Living_on_Margins_Final_July_2005 [accessed on 4/11/2014]
- Greene JA. An ethnography of non-adherence: culture, poverty, and tuberculosis in urban Bolivia. *Culture, Medicine and Psychiatry*. 2004; 28(3):401–425.
- Hadzibegovic DS, Maloney SA, Cookson ST, Oladele A. Determining TB rates and TB case burden for refugees. *International Journal of Tuberculosis and Lung Disease*. 2009; 9(4):409–414. [PubMed: 15830746]
- Ibararren S, Beck S, Pearce PF, Chirico C, Etchevarria M, Cardinale D, Rubinstein F. Text TB: a mixed method pilot study evaluating acceptance, feasibility, and exploring initial efficacy of a text messaging intervention to support TB treatment adherence. *Tuberculosis Research and Treatment*. 2013; :Article 349394.doi: 10.1155/2013/349394 [PubMed: 24455238]

- Ito KL. Health culture and the clinical encounter: Vietnamese refugees' responses to preventive drug treatment of inactive tuberculosis. *Medical Anthropology Quarterly*. 1999; 13(3):338–364. [PubMed: 10509313]
- Jaiswal A, Singh V, Ogden JA, et al. Adherence to tuberculosis treatment: lessons from the urban setting of Delhi, India. *Tropical Medicine and International Health*. 2003; 8(7):625–633. [PubMed: 12828545]
- Johansson E, Winkvist A. Trust and transparency in human encounters in tuberculosis control: lessons learned from Vietnam. *Qualitative Health Research*. 2002; 12(4):473–491. [PubMed: 11939249]
- Johansson E, Long NH, Diwan VK, Winkvist A. Attitudes to compliance with tuberculosis treatment among women and men in Vietnam. *International Journal of Tuberculosis and Lung Disease*. 1999; 3(10):862–868. [PubMed: 10524582]
- Jureidini R. Irregular workers in Egypt: migrant and refugee domestic workers. *International Journal on Multicultural Societies*. 2009; 11:75–90.
- Khan MA, Walley JD, Newell J, Imdad N. Tuberculosis in Pakistan: sociocultural constraints and opportunities in treatment. *Social Science and Medicine*. 2000; 50(2):247–254. [PubMed: 10619693]
- Khan MA, Walley JD, Witter SN, Shah SK, Javeed S. Tuberculosis patient adherence to direct observation: results of a social study in Pakistan. *Health Policy Plan*. 2005; 20(6):354–365. [PubMed: 16183735]
- Kimbrough W, Saliba V, Dahab M, Haskew C, Checchi F. The burden of tuberculosis in crisis affected populations: a systematic review. *The Lancet Infectious Diseases*. 2012; 12(12):950–965. [PubMed: 23174381]
- Kirwan DE, Nicholson BD, Baral SC, Newell JN. The social reality of migrant men with tuberculosis in Kathmandu: implications for DOT in practice. *Tropical Medicine and International Health*. 2009; 14(12):1442–1447. [PubMed: 19845920]
- Muhwezi W, Sam D. Adaptation of urban refugees in Uganda: a study of their socio-cultural and psychological well-being in Kampala city. *African Health Sciences*. 2004; 14(1):37–46.
- Munro S, Lewin SA, Smith HJ, Engel ME, Fretheim A, Volmink J. Patient adherence to tuberculosis treatment: a systematic review of qualitative research. *PLoS Medicine*. 2007; 4(7):e238. [PubMed: 17676945]
- Nair D, George A, Chacko K. Tuberculosis in Bombay: new insights from poor urban patients. *Health Policy Plan*. 1997; 12(1):77–85. [PubMed: 10166105]
- Rocha C, Montoya R, Zevallos K, Curatola A, Ynga W, Franco J, Evans CA. The innovative socio-economic interventions against tuberculosis (ISIAT) project: an operational assessment. *International Journal of Tuberculosis and Lung Disease*. 2011; 2:S50–S57. [PubMed: 21740659]
- Rysstad OG, Gallefoss F. TB status among Kosovar refugees. *International Journal of Tuberculosis and Lung Disease*. 2003; 7(5):458–463. [PubMed: 12757047]
- Stangl, AL.; Brady, L.; Fritz, K. [accessed on 4/11/2014] Technical brief: measuring HIV stigma and discrimination. 2012. Available at: r4d.dfid.gov.uk/Output/191539
- Thomas F, Roberts B, Luitel N, Upadhaya N, Tol WA. Resilience of refugees displaced in developing world: a qualitative analysis of strength and struggles of urban refugees in Nepal. *Conflict and Health*. 2011; 5(1):20. [PubMed: 21943401]
- Tomas BA, Pell C, Cavanillas AB, Solvas JG, Pool R, Roura M. Tuberculosis in Migrant Populations. A systematic review of the qualitative literature. *PLoS ONE*. 2013; 8(12):e8244.
- Volmink J, Garner P. Directly observed therapy for treating tuberculosis. *Cochrane Database System Review*. 2006; 19(2):CD003343.
- Wares DF, Singh S, Acharya AK, Dangi R. Adherence to tuberculosis treatment in the eastern Tarai of Nepal. *International Journal of Tuberculosis and Lung Disease*. 2003; 7(4):327–335. [PubMed: 12729337]
- Watkins RE, Plant AJ. Pathways to treatment for tuberculosis in Bali: patient perspectives. *Qualitative Health Research*. 2004; 14(5):691–703. [PubMed: 15107171]
- Wei X, Chen J, Chen P, et al. Barriers to TB care for rural-to-urban migrant TB patients in Shanghai: a qualitative study. *Tropical Medicine and International Health*. 2009; 14(7):754–760. [PubMed: 19392747]

- WHO. Addressing Poverty in TB Control, Options for National TB Control Programmes. World Health Organization; Geneva, Switzerland: 2005. Available at: http://whqlibdoc.who.int/hq/2005/who_htm_tb_2005.352.pdf [accessed on 4/11/2014]
- WHO. Tuberculosis Care and Control in Refugee and Displaced Populations: An Interagency Field Manual. 2. Ottmani: World Health Organization; Geneva, Switzerland: 2007. Available at: http://whqlibdoc.who.int/publications/2007/9789241595421_eng.pdf [accessed on 4/11/ 2014]
- Willems, R. Coping with displacement: social networking among urban refugees in an east African context. In: Ohta, I.; Gebre, YD., editors. Displacement Risks in Africa: Refugees, Resettles and Their Host Populations. Australia Trans Pacific Press; Australia: 2005. p. 53-77.
- World Health Organization. [accessed on 4/11/2014] Tuberculosis country profiles: Egypt. 2014a. Available at: <http://www.who.int/tb/country/data/profiles/en/>
- World Health Organization. [accessed on 4/11/2014] Draft global strategy and targets for tuberculosis prevention, care and control after 2015. 2014b. Available at: http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_11-en.pdf?ua=1
- World Health Organization & International Organization for Migration. [accessed on 4/11/2014] Tuberculosis prevention and care for migrants. 2014. Available at: www.who.int/tb/publications/WHOIOM_TBmigration
- Wyss LL, Alderman MK. Using theory to interpret beliefs in migrants diagnosed with latent TB. Online Journal of Issues in Nursing. 2007; 12(1):7. [PubMed: 21848354]
- Yamada S, Caballero J, Matsunaga DS, Augustin G, Magana M. Attitudes regarding tuberculosis in immigrants from the Philippines to the United States. Family Medicine. 1999; 31(7):477–482. [PubMed: 10425528]

What is known about this topic

- Tuberculosis inflicts major human suffering and loss in the world that resulted to 1.5 million deaths in 2013. It disproportionately affects poor and marginalised populations.
- TB treatment adherence is influenced by social determinants of health including material living conditions and psychological and behavioural risk factors.
- Migrants and refugees in urban settings have different risk factors than those in camps.

What this paper adds

- This study is significant and timely considering the current political conflicts in the Middle East and North Africa region with refugee influx in numerous urban settings.
- The study provides important information on poverty and social vulnerabilities of non-national TB patients during their treatment and suggests interventions that potentially improve livelihoods and combat seclusion and stigma in an urban setting.

Table 1

Themes and sub-themes

Themes	Sub-themes
Theme 1: poverty	Change in gender roles Stress of not being able to support family Stress of being dependant on others Fear of losing housing Lack of food Monotony of food
Theme 2: social context	Fear of infecting others Lack of opportunities to discuss TB Stigma Drivers Manifestations Outcomes